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Completion of Advance Directives Among U.S. Consumers

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Abstract

Background—Current, ongoing national surveys do not include questions about end-of-life (EOL) issues. In particular, population-based data are lacking regarding the factors associated with advance directive completion.

Purpose—To characterize U.S. adults who did and did not have an advance directive and examine factors associated with their completion, such as the presence of a chronic condition and regular source of health care.

Methods—Data were analyzed in 2013 from adults aged 18 years and older who participated in the 2009 or 2010 HealthStyles Survey, a mail panel survey designed to be representative of the U.S. population. Likelihood ratio tests were used to examine the associations between advance directive completion and demographic and socioeconomic variables (education, income, employment status); presence of a chronic condition; regular source of health care; and self-reported EOL concerns or discussions. Multiple logistic regression analyses identified independent predictors related to advance directive completion.

Results—Of the 7946 respondents, 26.3% had an advance directive. The most frequently reported reason for not having one was lack of awareness. Advance directive completion was associated with older age, more education, and higher income and was less frequent among non-white respondents. Respondents with advance directives also were more likely to report having a chronic disease and a regular source of care. Advance directives were less frequent among those who reported not knowing if they had an EOL concern.

Conclusions—These data indicate racial and educational disparities in advance directive completion and highlight the need for education about their role in facilitating EOL decisions.

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Introduction

Current demographic trends document a growing aging population in the U.S.¹ and an increase in the prevalence of chronic disease among adults 44 years or older.² Among older adults with chronic disease, studies document a 10-year increase in out-of-pocket spending² and Medicare expenditures.³ Although several investigations noted that healthcare costs are greatest during the final years of life,^{4,5} a recent analysis indicates that advance directives may have an influence on spending. Using linked personal interviews and Medicare claims data from beneficiaries who died between 1998 and 2007, researchers found that advance directives were associated with significantly lower levels of Medicare spending, a lower likelihood of in-hospital deaths, and increased hospice use in regions characterized by higher levels of end-of-life (EOL) spending.⁶

During the past 20 years, issues related to EOL care, such as high-profile legal cases and debates about coverage for advance care planning discussions, have attracted national attention.^{7–9} Although U.S. national polls and selected state surveys provide periodic insights into public perspectives regarding EOL issues, including their attitudes about advance directives,^{10–14} ongoing national surveys currently do not include EOL questions. In particular, population-based data are lacking regarding the factors associated with advance directive completion among adults aged 18 or older.

In 2002, Rao and colleagues framed EOL as a public health issue¹⁵ and subsequently documented the importance of collecting and analyzing population-based EOL data.¹⁶ As a consequence, EOL items were added to the 2009–2010 Porter Novelli HealthStyles surveys. The present study characterizes U.S. adults who did and did not have an advance directive and examines the factors that influence their completion. Of particular interest was understanding whether having a chronic condition, which are among the leading causes of death in the U.S.,¹⁷ and a regular source of health care was associated with having an advance directive.

Methods

Porter Novelli conducts the HealthStyles surveys using the Synovate consumer mail panel of community-dwelling adults.¹⁸ In 2009 and 2010, HealthStyles included 5 EOL questions. The appendix provides information on the survey methodology and EOL items (see Appendix A, www.ajpmonline.org).

Responses were received from 4556 HealthStyles participants in 2009 and 4184 in 2010, yielding overall response rates of 65% and 67%, respectively. The data were post-stratified and weighted by gender, age, income, race, and household size to reflect the distribution of the previous years' U.S. Current Population Survey. The weighting is based on an assumption that subgroups of the HealthStyles sample share the same (or homogeneous) views as similar subgroups of the general population.¹⁹ Prior analyses indicate that HealthStyles data produce similar estimates of self-reported behavioral risk factors and conditions to other population-based survey data.¹⁸ The EOL questions were derived from a systematic review of EOL surveys.²⁰ Respondents were asked three questions about whether

they discussed their treatment preferences and plans with others in the event of a serious illness; had an advance directive or their reasons for not having one; and had any concerns about EOL care. On the basis of the responses to the advance directives item, respondents were classified as having an advance directive or did not have an advance directive (latter category included “don’t know,” “never thought about signing one,” “do not need it...,” “some other reason” responses). Respondents with missing data for this item ($n=794$) were excluded from all analyses. The percentage of respondents reporting an advance directive in 2009 did not differ significantly from the percentage in 2010; hence, the data were combined for the 2 years.

The data were analyzed using R.²¹ Likelihood ratio tests were used to examine the associations between advance directives (yes, no) and demographic (age, gender, race/ethnicity, marital status) and socioeconomic variables (education, income, employment status); presence of a chronic condition; regular source of health care; and self-reported EOL concerns or discussions. A multivariable logistic regression model was used to examine the relationship between having an advance directive and having a chronic disease (yes, no/don’t know) and regular source of health care (yes, no/don’t know). The model controlled for age, gender, race/ethnicity, education, income, and EOL concerns (yes, no, don’t know). Only respondents with complete data for all of the variables (dependent, independent, and covariates) were included in the multivariate analysis ($n = 6763$). The data were weighted for all of the statistical analyses.

Results

A total of 7946 respondents were included in the sample (Table 1, column 1). Overall, 67.8% reported having concerns about EOL care, including concerns about the costs of care, the pain they might experience, or their comfort and dignity (data not shown). Approximately 18.8% reported no EOL concerns and 14.1% responded they did not know. Additionally, 48.7% of respondents reported having and 48.6% reported not having discussions about the treatment they wished to receive in the event of serious illness.

A total of 2093 (26.3%) respondents reported they had an advance directive whereas 5853 (74.7%) did not have one. The top 2 reasons respondents gave for not having an advance directive were “I don’t know what advance directives are” (24%) and “my family knows my wishes” (16.4%) (data not shown). Although respondents less than 54 years of age were most likely to report not having advance directives (68.3%), 31.7% of respondents 55 years of age or older also reported not having one. Advance directives were more frequent among women, whites, and respondents who had a college degree or post-graduate training, were married, and had a chronic disease and regular source of care (Table 1, columns 2 and 3). White respondents with at least some college were more likely to report having an advance directive (see Table 2). For black and Hispanic respondents, advance directives were less frequent across all educational groups. Respondents who reported “don’t know” to having EOL concerns were nearly 5 times as likely to not have an advance directive. Advance directives were less frequent among those who did not have an EOL discussion (Table 1).

In multivariate analyses, advance directives were significantly associated with age, income, education, and having a chronic disease and a regular source of health care (Table 3). Having EOL concerns was not significantly associated with having an advance directive, but people who did not know if they had an EOL concern were significantly less likely to have an advance directive. Compared to whites, blacks and Hispanics were less likely to have an advance directive.

Discussion

Approximately 25% of respondents reported having an advance directive; lack of awareness was the most frequently reported reason for not having one. Respondents with advance directives tended to be older, with more education and higher incomes, and to report having a chronic disease and a regular source of care. Whites were also more likely to have an advance directive than other racial and ethnic groups. These findings are consistent with other studies^{14,22–24} and reinforce the need for EOL communication strategies tailored to educational level and race/ethnicity. Interestingly, those who reported not knowing if they had an EOL concern were less likely to have an advance directive.

This study has several limitations. Respondents were community-dwelling adults who consented to participate in a mail panel survey, which may result in a selection bias. Although the survey did not include residents of nursing homes or assisted-living facilities or the homeless, the sampling strategy and post-stratification weighting help make the sample balanced with respect to U.S. household population. The survey provides self-reported information on respondents' attitudes and behaviors. Thus, information was lacking about the number or types of chronic health conditions or health status, and whether respondents had a living will, durable healthcare power of attorney, or both could not be determined. Others have noted that living wills cannot describe all of the circumstances that patients may find themselves in²⁵ and may have limited effectiveness. Because the data are cross-sectional, causality cannot be established. The survey items had structured responses, which may have influenced respondents. Despite these limitations, the study provides information from a large sample of adults on their attitudes and behaviors regarding advance directives. Prior studies have focused on clinical populations, state samples or certain age groups (e.g., older adults).

People who lack the knowledge to have EOL concerns or discussions or about the role of advance directives in facilitating EOL decisions may represent potential targets for intervention. Tools^{26,27} have been developed to help consumers and their family members develop an understanding of EOL issues and facilitate decision making; broader dissemination of these tools would assist in increasing their use. Although survey data¹⁴ suggest that most people would prefer receiving EOL information from providers, physicians' attitudes and comfort level may be a barrier to these conversations.²⁸ Communication interventions²⁹ may help improve physicians' skills in discussing EOL issues with patients. Finally, recent studies^{30,31} have integrated information about advance directives for providers and patients into clinical decision support systems and found a positive effect on the rates of advance directive completion.

Given the current discussions about implementing different models of healthcare delivery, including the patient-centered medical home, EOL issues need to come to the forefront of planning efforts. We hope these findings will contribute to current national conversations³² about EOL care.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Appendix: Supplementary data

Supplementary data associated with this article can be found, in the online version, at <http://dx.doi.org/10.1016/j.amepre.2013.09.008>.

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Table 1Characteristics of survey respondents with and without advance directives^a

	Total N = 7946 ^b n	Has advance directive N = 2093 (26.3%) n (%) ^c	Does not have advance directive N = 5853 (74.7%) n (%)	p-value ^d
Year of survey	7946	2093 (26.3)	5853 (73.7)	0.996
2009	4199	1105 (26.3)	3094 (73.7)	
2010	3747	988 (26.4)	2759 (73.6)	
Gender	7946	2093 (26.3)	5853 (73.7)	<0.001
Male	3862	965 (25)	2897 (75)	
Female	4084	1128 (27.6)	2956 (72.4)	
Age, years	7946	2093 (26.3)	5853 (73.7)	<0.001
18–34	979	116 (11.8)	863 (88.2)	
35–54	3879	746 (19.2)	3133 (80.8)	
55–65	1597	468 (29.3)	1129 (70.7)	
65	1491	763 (51.2)	728 (48.8)	
Race	7946	2093 (26.3)	5853 (73.7)	<0.001
White	5225	1605 (30.7)	3620 (69.3)	
Black	1006	171 (17)	835 (83)	
Hispanic	1063	178 (16.7)	885 (83.3)	
Other	652	139 (21.3)	513 (78.7)	
Education	7885	2075 (26.3)	5810 (73.7)	<0.001
<High school graduate	476	68 (14.3)	408 (85.7)	
High school graduate	1891	393 (20.8)	1498 (79.2)	
Some college	2907	740 (25.5)	2167 (74.5)	
College graduate	1511	461 (30.5)	1050 (69.5)	
Post graduate	1100	413 (37.5)	687 (62.5)	
Marital status	7940	2091 (26.3)	5849 (73.7)	<0.001
Married/domestic partnership	5616	1495 (26.6)	4121 (73.4)	
Divorced/separated	877	231 (26.6)	646 (73.7)	

	Total N = 7946 ^b n	Has advance directive N = 2093 (26.3%) n (%) ^c	Does not have advance directive N = 5853 (74.7%) n (%)	p-value ^d
Widowed	441	207 (46.9)	234 (53.1)	
Single	1006	158 (15.7)	848 (84.3)	
Income, \$	7946	2091 (26.3)	5849 (73.7)	<0.001
24,999	2019	417 (20.7)	1602 (73.7)	
25,000–49,999	1594	387 (24.3)	1207 (79.3)	
50,000–74,999	1357	348 (25.6)	1009 (75.7)	
75,000	2976	941 (31.6)	2035 (68.4)	
Employment	7946	2093 (26.3)	5820 (73.7)	<0.001
Employed ^e	5127	1136 (22.2)	3991 (77.8)	
Not employed ^f	2773	944 (34)	1829 (66)	
Has chronic disease	7946	2093 (26.3)	5853 (73.7)	<0.001
Yes	2961	986 (33.3)	1975 (66.7)	
No	4757	1061 (22.3)	3696 (77.7)	
Don't know	228	46 (20.2)	182 (79.8)	
Regular source of care	7946	2093 (26.3)	5853 (73.7)	<0.001
Yes	7059	1970 (27.9)	5089 (72.1)	
No	768	103 (13.4)	665 (86.6)	
Don't know	119	20 (16.8)	99 (83.2)	
End-of-life concerns	7081	1857 (26.2)	5224 (73.8)	<0.001
Yes	4804	1315 (27.4)	3489 (72.6)	
No	1278	382 (29.9)	896 (70.1)	
Don't know	999	160 (16)	839 (84)	
End-of-life discussion	7946	2093 (26.3)	5853 (73.7)	<0.001
Yes	3868	1704 (44.1)	2164 (55.9)	
No	3866	342 (8.8)	3524 (91.2)	
Don't know	212	47 (22.2)	165 (77.8)	

^a Based on raw data from the 2009 and 2010 HealthStyles Survey

^b7946 respondents answered the advance directive item. For some of the independent variables (education, marital status, EOL concerns), there were missing data. In these cases, the total N for the bivariate comparisons was less than 7946.

^cPercentages are row percentages.

^dFrom a weighted likelihood ratio test

^eIncludes full-time and part-time employment

^fIncludes retired and unemployed

Table 2

Characteristics of survey respondents with and without advance directives according to educational level and stratified by race/ethnicity,^a n (%)^b

	Has advance directive	Does not have advance directive
White	1592 (30.6)	3605 (69.4)
<High school graduate	47 (20.1)	187 (79.9)
High school graduate	303 (24.2)	950 (75.8)
Some college	559 (30)	1305 (70)
College graduate	360 (33.7)	707 (66.3)
Post-graduate	323 (41.5)	456 (58.5)
Black	169 (17)	824 (83)
<High school graduate	7 (10.1)	62 (89.9)
High school graduate	40 (15.6)	216 (84.4)
Some college	59 (14.6)	346 (85.5)
College graduate	35 (23.2)	116 (76.8)
Post-graduate	28 (25)	84 (75)
Hispanic	175 (16.7)	876 (83.3)
<High school graduate	11 (8.3)	122 (91.7)
High school graduate	37 (13.5)	237 (86.5)
Some college	72 (17.3)	343 (82.7)
College graduate	24 (18)	109 (82)
Post-graduate	31 (32.3)	65 (67.7)
Other	139 (21.6)	505 (78.4)
<High school graduate	3 (7.5)	37 (92.5)
High school graduate	13 (12)	95 (88)
Some college	50 (22.4)	173 (77.6)
College graduate	42 (26.3)	118 (73.8)
Post-graduate	31 (27.4)	82 (72.6)

^aThis analysis required respondents to have complete data for race, education, and the advance directive items. Thus, there may be differences between the total numbers for race in this table and Table 1 (which only required complete data for individual bivariate comparisons).

^b Percentages represent row percentages.

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Table 3Association between reported chronic disease and regular source of health care and advance directives^a

Factor	OR (95% CI)
Chronic disease	
No	ref
Yes	1.58 (1.38, 1.81)
Regular source of care	
No	ref
Yes	1.64 (1.29, 2.12)
Age, years	
18–34	ref
35–54	1.59 (1.34, 1.91)
55–64	3.27 (2.68, 4.00)
65	8.1 (6.63, 9.92)
Gender	
Female	ref
Male	0.68 (0.60, 0.77)
Race	
White	ref
Black	0.69 (0.55, 0.85)
Hispanic	0.77 (0.63, 0.94)
Other	0.73 (0.55, 0.97)
Education	
<High school graduate	ref
High school graduate	1.86 (1.28, 2.76)
Some college	2.21 (1.53, 3.25)
College graduate	3.21 (2.19, 4.81)
Post graduate	3.05 (2.06, 4.59)
Income, \$	

Factor	OR (95% CI)
24,999	ref
25,000–49,999	1.22 (1.003, 1.49)
50,000–74,999	1.48 (1.20, 1.82)
75,000	1.78 (1.48, 2.16)
End-of-life concerns	
No concerns	ref
Don't know	0.56 (0.44, 0.71)
Has concerns	0.89 (0.76, 1.05)

^aMultivariate logistic regression analysis involving data from 2009 and 2010 HealthStyles Surveys; the model was adjusted for age, gender, race, income, education, and end-of-life concerns.